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AUTHOR(S):

NISHI, Makoto

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RISK, KNOWLEDGE, AND ETHICS IN THE ERA OF GLOBAL HEALTH: HIV INTERVENTIONS AND LOCAL RESPONSES AMONG THE GURAGE

Makoto NISHI

Global Survivability Studies Unit, Kyoto University

ABSTRACT The global health framework is one of the technological and institutional foundations of human survival in the contemporary world. Within this framework, infectious disease epidemiology serves as the knowledge base of efforts to control epidemics. The effectiveness of such epidemiological information requires that we have a clear understanding of how certain behaviors of certain individuals present risks to others. When a particular group of people are considered a risk to others, we face an ethical dilemma concerning how to establish an affirmative relationship between the two parties.

This paper examines knowledge, institutions, and ethical issues related to human survival in the context of the spread of pathogens. It identifies the challenges faced by households affected by HIV through examples drawn from Gurage, a provincial area in southern Ethiopia, and focuses on challenges related to the livelihood, remarriage, and childbirth of women who have lost their husbands to HIV and who, themselves, are HIV-positive. Responses of local health workers to the problems faced by such women and by households affected by HIV will also be examined.

Key Words: Farm labor; Gurage; Health workers; HIV; Risk of infection.

INTRODUCTION

Infectious disease epidemiology provides the fundamental knowledge underlying efforts by global health institutions to control the spread of intractable viruses. Although this knowledge serves as the basis for technologies and institutions that enable humans to coexist with viruses, it also presents us with ethical dilemmas related to the fact that “a case may also be a risk factor” for the spread of disease (Giesecke, 2002: 4). An epidemiological approach to controlling the spread of disease is necessary for people to be able to live with infectious diseases. At the same time, a clear understanding of the risks that certain behaviors pose to others is necessary for epidemiological interventions to be valid. When a given individual constitutes a risk to another individual, we are faced with the ethical question of how to create an affirmative relationship between these individuals.

It is estimated that over 34 million individuals around the world are living with HIV. Of these, two-thirds live in sub-Saharan Africa, where the HIV infection rate of adults between the ages of 15 and 49 has reached 4.9% (UNAIDS, 2012). People living in Africa are facing the question of how those infected and those not infected by HIV should relate to one another in daily life. In this paper, I explore how affirmative relationships between persons with different HIV statuses can be developed and maintained in a rural Ethiopian setting. Such ethical relationships,

I believe, are the most important sources of social resilience in the face of HIV and other pathogen invasions.

As a result of HIV/AIDS interventions in recent years, the number of new HIV transmissions is on the decline in sub-Saharan Africa (UNAIDS, 2012). At the same time, an increasing number of families and community members are aware that they are living with HIV-positive members as a result of the widespread implementation of HIV screening. Following progress in creating an institutional infrastructure to provide inexpensive antiretroviral drugs in low-income countries, increasing numbers of HIV-positive individuals in Africa are now being treated. Meanwhile, an increasing number of people living with the virus wish to have and raise children due to the extended life expectancies of those who receive HIV treatment. Marriage and childrearing by HIV-positive individuals have become topics of debate because the issues they raise cannot be fully resolved within the existing moral framework. It is important not only to advocate for the right to treatment but also to recognize that HIV-positive individuals receiving treatment “are not going to die, but live, and part of living is about reproducing and having kids” (Harries et al., 2007).

In this paper, I identify the challenges faced by household members affected by HIV through examples drawn from an agrarian Gurage village in southern Ethiopia. I investigated the experiences of women infected with HIV who have lost their husbands to AIDS with regard to livelihood, remarriage, and childbirth and childrearing. Given that these women living with HIV could present a risk of HIV transmission to other local residents through their sexual relations and to their children through childbirth, it is easy for them to be ostracized. However, we can also observe practices among some Gurage villagers that support the livelihoods of such women. Moreover, several healthcare workers in the local community are proactively providing the information necessary for these women to have children.

This paper is organized as follows. In the following section, “Humans and Pathogens,” I identify the technologies, institutions, and ethical conditions necessary for people to coexist with pathogens, taking into consideration the historical development of the global health framework. In the section titled “Development of the Healthcare System in Rural Ethiopia,” I describe the development of global efforts to combat HIV/AIDS and examine interventions undertaken in Ethiopian villages as concrete examples of these global efforts. In the section titled “Living with the Virus,” I examine issues faced by households affected by HIV by focusing on concrete examples drawn from Gurage villages in southern Ethiopia. In the concluding section, I consider some of the conditions necessary for those living with the virus to develop affirmative relationships with those who are not, thereby enabling members of both groups to have fulfilling lives.

HUMANS AND PATHOGENS

Surviving Pathogen Invasions

Pathogens are an important regulator of relationships with nature (McNeill, 1998), and epidemics caused by pathogens have frequently played a definitive role in human history. Pathogens prompted the collapse of the Inca Empire in the 16th century (Diamond, 1997) and prevented Europeans from settling in tropical Africa in the early 19th century (Curtin, 1989). It is possible to describe these events as “value-neutral” processes; although the Spanish in the 16th century may have harbored ill will towards the Inca, they could not have imagined that the smallpox virus they introduced would have such a devastating effect on the Incan population. Indeed, even some good-willed Spaniards would have had no way of knowing how to immunize the Incas against smallpox. Those who tolerated the pathogen for some reason survived, and those who did not, died out. In this case, survival was simply a matter of chance that did not involve the ethical structure of human society. Alternatively, one might say that survival largely followed the logic of nature.

The same cannot be said of the factors that determine who survives HIV in the present day. This is because the technological situation has changed, and this change has altered the ethical possibilities. We now know how to screen and treat HIV infectious diseases. The development of HIV treatment has led to ethical questions about who should have access to treatment. As a result, the global community has engaged in efforts to provide access to treatment to infected individuals in poor countries. In the decade leading up to 2012, great advances have been made in creating a global framework for the treatment of the HIV infection. It can be said that this victory was won by the collective actions of those living with HIV/AIDS.

However, this outcome certainly does not mean that people have won the battle against HIV or gained control over the virus. Current HIV drugs cannot completely cure the virus. The function of HIV drugs is to suppress replication of the virus in the body and thereby create conditions under which the human body can coexist with the virus. HIV drugs are one of the technological conditions necessary for humans to coexist with HIV.

Tropical Medicine and Global Health

HIV is one of the primary foci of the global framework for medical intervention, which is often referred to as “global health.” The latter encompasses health issues that transcend national boundaries and incorporates the institutional framework and knowledge necessary to deal with such issues. In a global-health approach, various actors—including international organizations such as the World Health Organization (WHO) and the Joint United Nations Program on HIV and AIDS (UNAIDS), individual nations and their healthcare systems, international and local NGOs, as well as research institutes—work together by drawing on knowledge from a wide

range of disciplines, including medicine, epidemiology, public health, behavioral science, and sociology, to protect the health of individuals around the world.

We can trace the roots of global health to the development of tropical medicine during the 19th century. Tropical diseases such as malaria and yellow fever were the primary threat to Europeans attempting to manage tropical colonies. The rate of malaria infection among European colonists was extremely high, particularly in Western Africa, which was feared as the “white man’s graveyard.”⁽¹⁾ What changed this state of affairs was the discovery of quinine as a treatment for malaria. The mortality rate of Europeans stationed in tropical colonies fell dramatically between the 1840s and 1870s (Curtin, 1994). It was the ability to survive the malaria parasite that allowed Europeans to accelerate their colonization of tropical Africa.

The efforts of Albert Schweitzer to provide modern medicine to the people of Africa notwithstanding, it would be a significant stretch to say that the tropical medicine practiced in the 19th and early 20th century formed a basis for a sustainable humanosphere of people living in the tropics. In fact, it was just the opposite. Tropical medicine enabled the major European powers to divide and conquer Africa. The ethical decisions made by practitioners of tropical medicine were, at the time, prescribed primarily by the logic of colonial rule.

Global health focuses on infectious diseases such as malaria, tuberculosis, and, more recently, HIV infectious diseases. Although AIDS used to be considered a “fatal disease,” the development of antiretroviral treatment has substantially improved the life expectancy of infected individuals. It is reported that, in high-income countries, HIV-positive individuals in treatment at age 20 can expect to live an additional 50 years (Antiretroviral Therapy Cohort Collaboration, 2008). This is not substantially different from the average life expectancy in their respective countries. HIV drug treatments were introduced in wealthy countries starting in the late 1990s, resulting in a remarkable improvement in the life expectancy of HIV-positive individuals. Meanwhile, the majority of infected individuals in poor countries had limited access to these expensive treatments. The international pharmaceutical companies that contributed to the development of HIV drugs initially refused to permit the manufacture of generic versions of their drugs on the pretext of protecting their intellectual property rights.

However, the ethical possibilities of present-day global health are not always controlled by the actors in wealthy countries. Facing the global movements of HIV activists, the international pharmaceutical companies were forced to concede to demands, albeit only partially, by infected individuals in poor countries for access to treatment. Today, global health serves as the major arena for advocacy related to the ethics of the universal right to healthcare. As Garrett accurately stated, global health is the movement under which “for the first time in history, the world is poised to spend enormous resources to conquer the diseases of the poor” (Garrett, 2007: 14).⁽²⁾

Between 2001 and the present, we have witnessed the development of a global institutional infrastructure designed to provide inexpensive drugs, manufactured in countries such as India and Brazil, to infected individuals in poor countries. It has been reported that, at present, the life expectancy of HIV-positive individuals

receiving appropriate treatment in some low-income countries is close to the average life expectancy of the general population in their respective countries.⁽³⁾

Infectious Disease Epidemiology and Interventions to Prevent HIV Infection

The protection of people from infectious diseases requires that we not only treat those who have already been infected but also that we establish institutions capable of implementing technologies to halt the spread of diseases. Elucidation of the infection route of malaria marked a critical turning point in the development of tropical medicine. Clarification of the role played by a certain group of mosquitoes (*Anopheles* spp.), enabled management of the disease through vector control by the end of the 19th century. On a global scale, the number of deaths due to malaria declined dramatically between the early 20th century and the 1960s (Carter & Mendis, 2002: 583).⁽⁴⁾

In present-day global health, infectious disease epidemiology is the discipline that provides the knowledge base for the development of measures to control the spread of pathogens. Epidemiology involves the description, analysis, and understanding of patterns of disease within populations. Although infectious disease epidemiology involves elements of an infectious disease's natural history, including its incubation period, symptom development, and mortality, its primary focus is on "social" aspects such as infection route, vulnerable populations, and preventive measures. Epidemiologists working on HIV have a direct interest in the sexual and non-sexual routes of transmission as well as in sexual behavior patterns (Giesecke, 2002). Unlike malaria, the HIV infection route has no vector aside from humans. For this reason, preventive interventions for HIV focus on controlling those individual behaviors that increase the risk of infection.

Infectious disease epidemiology provides the knowledge for the development of effective preventive interventions to control epidemics. The most salient feature of infectious disease epidemiology is that patients themselves may become risk factors for the spread of disease (Giesecke, 2002: 4). Knowledge of infectious disease epidemiology is valid only when the relevant actors have a clear understanding of what certain behaviors mean in terms of the risk of infection they pose to other individuals. Given that people's behavior patterns determine the risk of disease spread, an important challenge for preventive interventions can involve the promotion of changes in people's behavior. However, the specific changes in behavior that will result in halting the spread of HIV are the subjects of constant debate. In the 1990s, campaigns in Uganda promoting the reduction of the number of sexual partners are said to have led to the decline in HIV infection rates. However, it has also been noted that similar campaigns in other countries did not result in the desired change in behavior (Stoneburner, 2004).

In 2003, the Bush administration launched the United States President's Emergency Plan for AIDS Relief (PEPFAR). The plan is known for its so-called "moral approach," that is, its emphasis on strict abstinence and being faithful. In this context, abstinence means not engaging in sexual relations until marriage, and being faithful means not engaging in sexual relations with partners other than one's spouse. In 2006, the *Lancet* published a criticism of PEPFAR's approach

for being detached from the realities on the ground and, as a result, hindering other effective preventive interventions (Lancet, 2006).

A strict moral approach can be effective only if it is possible to completely control people's behavior. Preventive interventions based on abstinence and faithfulness make the mistake of trivializing the complexities of infectious disease epidemiology. The legitimacy of epidemiology, and of HIV preventive interventions based on this knowledge base, is rooted in the ability to provide knowledge that can help to prevent the spread of infection in the context of an understanding that people behave in many different ways. From the standpoint of developing effective preventive interventions, it may be more appropriate to view the role of infectious disease epidemiology as providing knowledge to enable people to coexist with HIV rather than as a means of completely eradicating it. In contrast, the moral approach rests on the premise that transmission of the virus can be prevented by penalizing individuals designated as being immoral.

The role that should be played by HIV preventive interventions involves accurately gauging the state of epidemics and providing people with methods to avoid the risk of infection. "Most HIV infections in sub-Saharan Africa occur as a result of heterosexual intercourse between couples. Women who are infected by HIV seropositive partners risk infecting their infants in turn" (Painter, 2001: 1397). HIV screening provides an opportunity for couples to avoid risky behaviors and, thus, to lower the possibility of transmission. Adopting this viewpoint, Painter concluded that promotion of voluntary counseling and testing (VCT)⁽⁵⁾ would be an effective HIV preventive intervention in sub-Saharan Africa (Painter, 2001).

It is important that we do not prioritize a moral approach to HIV prevention but, instead, implement HIV interventions based on epidemiological data. However, it is also important to note that such interventions do, nevertheless, raise ethical dilemmas of their own. Although the number of new HIV infections is now on a downward trend in sub-Saharan Africa, the widespread introduction of HIV screening has resulted in increasing reports of serodiscordant couples (Guthrie et al., 2007). Additionally, the increase in life expectancy of infected individuals as a result of treatment has led to an increasing number of infected individuals who want to have children (Cooper et al., 2007; Kaida et al., 2011). What does it mean for serodiscordant couples to continue to live together while caring for each other's health (Nishi, 2011)? And what conditions are necessary to allow women to bear children in the context of the risk of mother-child transmission? In other words, what are the necessary conditions for creating affirmative relationships between those who are infected with the virus and those who are not in a given community? The answers to these questions raise issues that differ from those encountered when attempting to communicate accurate information about the risk of HIV transmission. Before considering answers to these questions, I briefly describe the development of the healthcare system in Ethiopia to demonstrate how global health interventions are being implemented in a rural African setting.

DEVELOPMENT OF THE HEALTHCARE SYSTEM IN RURAL ETHIOPIA

For global health interventions to be implemented effectively in low-income countries such as Ethiopia, it is important to first establish a working domestic healthcare system. Until the late 1990s, the Ethiopian healthcare system was woefully inadequate and, in rural areas, it was almost non-existent. However, the Ethiopian government's Health Sector Development Program (HSDP), implemented in four stages starting in 1997, has begun to produce significant changes.⁽⁶⁾ In 1997, when the government started the first phase of the HSDP, only 247 health centers were in existence. By 2008, the number of health centers had grown to 824, and 11,000 health posts had been established. Additionally, whereas only 5% of women had received antenatal care in 1997, 42% of women had reportedly made at least one antenatal visit to a healthcare facility in 2005, the year marking the end of the HSDP-II (MOH, 2005; 2008). Furthermore, the Ethiopian government has deployed health extension workers to local communities to serve as primary healthcare providers at the community level. The qualification for becoming a health extension worker is 10 years of primary and secondary education followed by a certain level of specialized training at one of the technical and vocational education and training institutions (TVETs) located throughout Ethiopia. More than 30,000 new health extension workers were trained and deployed between 2005 and 2009 (Koblinsky et al., 2010). It is assumed that health extension workers will be deployed as close to their villages of origin as possible.⁽⁷⁾ This is because, of all the healthcare workers in Ethiopia's healthcare system, these are the ones expected to work in closest contact with local residents.⁽⁸⁾

In the context of the improvement in Ethiopia's healthcare system and the abundant funds provided by global health institutions for HIV intervention, efforts to combat the virus have expanded rapidly. Until 2007, HIV screening was offered at health centers only in the form of VCT. Starting in 2008, expectant and nursing mothers have been encouraged to undergo HIV screening as part of the Preventing Mother-to-Child Transmission Program. Furthermore, the Provider-initiated HIV Counseling and Testing Program, whereby individuals visiting health centers who meet a certain set of criteria and provide agreement undergo HIV testing and counseling, was introduced in 2009.⁽⁹⁾

Free HIV screening services are offered at each of the five health centers located in the Enemorna Ener District (*wereda*) in the Gurage Zone. The number of HIV tests administered at one of these health centers increased dramatically: From 1,590 in 2007 to 3,017 in 2008 and to 12,718 in 2009. HIV screening is not the only service offered by health centers; health extension workers provide "community HIV testing," whereby they travel among villages and, upon consent, administer HIV tests and offer counseling to individuals on the spot using portable HIV screening kits. Furthermore, between mid- and late-September of each year, temporary testing centers are set up in various locations around the county. During this period, an important holiday for members of the Ethiopian Orthodox Church, Christian Gurages living in cities return *en masse* to their communities of origin to celebrate the Mesqal festival with their families.⁽¹⁰⁾

Although the healthcare institutions in rural Ethiopia are still in their early

stage of development, they have made great progress given their status as nearly non-existent only 15 years ago. This progress was made possible by the commitment of the Ethiopian government and the global health institutions.

LIVING WITH THE VIRUS

Access to screening and treatment is critical to the ability of residents of rural Ethiopian regions to survive HIV infectious diseases. Screening enables individuals to know their own infection status, and treatment enables HIV-positive individuals to survive. In the Gurage Zone, HIV treatment became readily accessible after 2005, leading to the possibility of improving or maintaining the health of people with the virus. Consider, for example, Ibrahim (not his real name), an unmarried male living with his mother and younger sister. Sometime in 2007, he began to experience obvious weight loss and decreased strength that, at one point, rendered even walking difficult. His health improved rapidly after starting antiretroviral drugs. When I met Ibrahim in August 2009, he was not only performing farm labor to support his family but was also earning cash as a day laborer constructing local roads and schools.⁽¹¹⁾ People who have seen the recovery of individuals who have received the antiretroviral drug that Ethiopians call *idme merazamiya medhanit* (the life-prolonging drug) no longer view HIV as the cause of a “fatal disease.”

Unfortunately, in some cases, the treatment of HIV-positive individuals is hindered by clear misunderstandings about the nature of the virus. A female health extension worker at a health center in Enemorna Ener District told me of a woman who was HIV-positive but refused all treatment. The woman argued that, “It is better to die drinking coffee than to live taking the drugs.” For Gurage women, brewing and serving coffee is the most important occasion for expressing their love and respect for their neighbors. Conversely, it is the greatest humiliation for an individual to be in a situation where coffee is being served and to not be offered a cup of coffee. She feared that, if she began taking the drugs, her neighbors would notice that she was HIV-positive and stop offering her coffee for fear of getting AIDS from the cup touched by her lips.

Such discrimination based on misunderstandings can be mitigated by appropriate education about HIV. However, there are cases in which individuals encounter problems even when others have a “correct understanding” regarding HIV.

As discussed above, knowledge of epidemiology encourages people to consider infected individuals as “risks.” Women living with HIV can present an epidemiological risk to other community members through sexual relations and to their children through childbirth. Living with HIV does not simply mean prolonging life. The question that arises here is whether such individuals can place themselves in situations that enable them to lead productive and meaningful lives within the context of their social and cultural relationships with other members of their community. In the remainder of this section, I examine how people affected by the virus attempt to answer that question in particular settings in rural Gurage society.

Households Affected by HIV

Tigist (not her real name) is a 30-year-old woman living in a rural Gurage village. Accompanied by Debitu Zema, a health extension worker employed by the local health center, I visited Tigist in August 2009. Tigist had three children, the oldest of whom was a 12-year-old boy. Her husband had passed away in 2004, presumably as a result of AIDS-related complications. Experiencing changes in her own health following her husband's death, Tigist was tested and informed that she was HIV-positive. Her youngest daughter, who was five years old at the time, also tested positive for the virus.

Since the death of her husband, Tigist and her family have encountered difficulties maintaining their household economy. While Tigist's husband was alive, he was a typical migrant laborer, working in Addis Ababa for the greater part of the year and sending money to Tigist, who continued to live in the village. With the money, Tigist hired local men to cultivate their *jegar* (backyard), which typically consists of a field adjacent to the family residence that is planted primarily with the staple crop known as ensete. Ensete is an important source of nutrients for Gurage farmers, and "cultivating the backyard" generally refers to planting and transplanting ensete. The perennial ensete is a member of the Musaceae (banana) family and reaches a height of more than 5 m at maturity. Shigeta considers ensete cultivation to be a model system for sustainable intensive agriculture in Africa (Shigeta, 2002).

The cultivation and processing of ensete is labor-intensive.⁽¹²⁾ Although ensete is a close relative of the banana, its fruit is not suitable for consumption; it is the starch stored in its thick stem-like part (pseudostem) and in the underground roots that is processed and eaten. The starch is scraped from the pseudostem, buried underground and allowed to ferment; this is then prepared for consumption after carefully removing the fibrous residue. Farm activities prior to harvest are also important. Gurage farmers transplant the ensete three or four times prior to harvest. Unless ensete is transplanted at the appropriate stage of growth, it does not develop to its full potential, making it difficult to obtain sufficient starch to feed the household. The transplanting of ensete is considered men's work, whereas the processing of ensete for consumption is considered women's work. With the death of her husband, Tigist lost her source of cash income and, along with it, the ability to hire the necessary male labor. Unable to perform appropriate ensete transplantations, the yield of her already meager backyard continued to decline.

Cultivate Your Neighbor's Backyard

Tigist's experience can be said to be typical of households in Gurage villages affected by HIV. The phrase "cultivate your neighbor's backyard" emerged often in my interviews with *bariq* or village elders and health workers when I asked about possible community measures to cope with the negative impacts of HIV on household activities. In this context, "cultivate your neighbor's backyard" refers to the practice, based on local custom, of extending economic support to households affected by HIV.

In Gurage villages, ensete is usually cultivated and processed by neighborhood labor cooperatives known in the local language as *gyez*. Several neighboring households form a group and perform farm activities at each household in turn. Separate *gyez* are formed based on gender, with the male *gyez* responsible for planting and transplanting ensete and the female *gyez* responsible for processing ensete. Male *gyez* generally comprise five or six households, and membership is likely to remain stable for years. Members of *gyez* are not necessarily related to one another. Instead, *gyez* can be formed as the members see fit, based on such criteria as friendship or being compatible in their farming practices. *Gyez* members do not simply work together; they become, in a certain sense, economically responsible for one another's households. For example, one Gurage farmer explained that if one of the other members of his *gyez* were to pass away and leave behind his wife and young children, his *gyez* would cultivate their backyard until the male child of the deceased member was old enough to take part in *gyez* labor. Additionally, it is possible for *gyez* members to "lend" their *gyez* to another impoverished household (usually a relative who is not a member of the *gyez*). In other words, they are able to ask the *gyez* to cultivate another household's backyard instead of their own. In Gurage villages, *gyez* serve as an important "safety net" for securing access to labor.

However, the principle of mutual help does not appear to apply in the case of Tigist's household. Because Tigist's husband had relocated his economic base to Addis Ababa and because the money he remitted was used to hire labor, they had not developed the long-term relationships or sense of mutual commitment to other households that emerge through a *gyez*. Furthermore, it appeared that there were no relatives living nearby who could "lend" their *gyez* to Tigist.

In March 2010, I visited three households affected by HIV. The first was Tigist's household, which I had visited the previous year. Thanks to the help with transplanting the ensete provided by neighboring farmers, the state of the backyard had improved a little, although it was unclear at that point whether this help was a unique event or if it could be relied on over the long term. The remaining two households were similar to Tigist's; each consisted of a HIV-positive woman with young children whose husband had passed away. One of the women had become impoverished after finding it difficult to continue to cultivate her backyard after the death of her husband and had moved into her parent's house, leaving the backyard abandoned. Neither she nor Tigist appeared to be receiving the appropriate HIV treatment. Today, HIV treatment in Ethiopia is provided free of charge. However, neither of these women had the money to pay the bus fare needed to visit the healthcare center located in a town more than 40 km away.⁽¹³⁾

The last household that I visited was Alganesh's (not her real name). She was a mother in her 20s with three children, the oldest of whom was an 11-year-old boy. Alganesh's backyard was small and consisted of what local farmers call "dry land," soil unsuitable for ensete cultivation. As in Tigist's case, it was evident that her household had not been wealthy even before her husband's death. What was different about Alganesh's household was that as soon as we were invited into her house, her neighbors brewed coffee and began to gather in her home carrying roasted barley. In Gurage villages, all adult members of neighboring

households are strongly encouraged to participate in the welcoming of visitors. I was unable to determine whether Tigist's neighbors did not bring coffee due to her HIV-positive status or some other reason. In any case, Tigist's isolation was obvious. In contrast, Alganesh clearly lived as a member of the village community. According to Debitu, the health extension worker who facilitated my visits, Alganesh's neighbors regularly helped to care for her household in various ways, including helping with ensete cultivation in her backyard, providing meals, and taking care of her livestock when she had to leave town to receive antiretroviral drugs. The well-cared-for state of her small backyard was a clear indication of the contribution of her neighbors.

Alganesh's husband had passed away three years earlier. When her husband's health began to deteriorate, they suspected HIV infection and visited the health center together to get tested. The results showed that both of them were infected. Whereas Alganesh's husband was devastated by the results, Alganesh accepted them calmly. Although it was evident that Alganesh's tough and cheerful disposition was one of the reasons people were drawn to her, Debitu told me that her neighbors were concerned for her for another reason as well. According to Debitu, they were "grateful" that Alganesh had announced her HIV-positive status immediately after receiving the results of the HIV test.

It is usual for Gurage women to remarry after losing a husband to either death or separation. It was likely that the still-young Alganesh would receive proposals for marriage or that a man who would try to force her to marry him despite her disinterest. At the same time, Alganesh had many reasons not to reveal her status, given that she could end up in poverty, because announcing her HIV-positive status could decrease her opportunities for remarriage. In such circumstances, she could be left without male labor to cultivate her backyard, given that her son was not yet old enough to assume that responsibility. Alganesh's proactive announcement of her HIV-positive status, made in spite of the potential negative consequences, was seen as an act of concern for the health of her neighbors. The villagers decided to care for Alganesh and support her household as a sign of gratitude for her concern.

It is important to note that Alganesh's case does not indicate that everything will go positively if an HIV-positive individual openly declares his/her status. Tigist neither proactively announced her HIV-positive status nor tried to deny it. That she was HIV-positive was simply a fact known by those around her. Tigist's ambivalent attitude is understandable in the context of a contemporary world in which HIV-positive individuals face both stigma and accommodation. Thus, to assert, after the fact, that Tigist was isolated from her neighbors because she did not proactively declare her HIV-positive status would be meaningless. In other words, the attitudes held by one party do not determine an entire relationship. The question here is whether a positive relationship based on mutual concern for each other's health can be established between those who are living with the virus and those who are not. Alganesh's case is important in that it demonstrates the actual possibility of developing such mutually affirmative relationships.

Childbirth by HIV-positive Women and the Role of Health Workers

This section addresses the issue of childbirth by HIV-positive women. Sarah (not her real name) is in her 20s. Originally from a rural Gurage village, she is currently residing in the city of Welqite, some 70 km from her village. Sarah married when she was in her teens. She was infected with HIV through her husband, a soldier, who had already passed away. When I visited Sarah in September 2007, she explained that, "It isn't possible to receive good medical treatment here, so even if I had a boyfriend, I would not think of having another child." For HIV-positive individuals in wealthy countries who want to have children, the risk of mother-child transmission of HIV can be reduced to extremely low levels by opting for caesarian section and not breast feeding. In contrast, the number of facilities in Ethiopia in which caesarian sections can be performed safely is limited. Feeding with formula is also not feasible, not only because it is too costly for most rural families, but also because of the limited availability of clean water.

It was only later that I found out that Sarah actually had a boyfriend at the time. In August 2009, she and her boyfriend had a daughter. I visited Sarah's house again 2 weeks after she had given birth. Soon after my arrival, three women from her village of origin came bearing clay pots filled with homemade butter and cheese. It was a gift to celebrate the birth of Sarah's daughter. Gurage villagers believe that nutrient-rich butter and cheese are the most important foods for women after giving birth, and married women present these to new mothers as a sign of celebration. All of the women were one generation older than Sarah, and two were relatives. The third woman was not related to Sarah, but there was a reason for her presence. This woman's son had spent some time in a detention center at the outskirts of Welqite city as a result of some trouble with his relatives. During this time, Sarah visited him almost daily, bringing food and water. The woman apparently wanted to repay her son's debt by celebrating the birth of Sarah's daughter.

That same month, I met Yafet Werqneh, who was the person in charge of HIV issues in the Enemorna Ener District Health Department. We talked about childbirth by HIV-positive women. He admitted that, in the past, some health workers had tried to convince HIV-positive individuals not to have children. Then he explained that he believed that this was a mistake. He came to believe that, given the inherent risk of mother-child transmission, the role of healthcare workers is not to discourage HIV-positive individuals from having children but, rather, to provide them with appropriate treatment and information to reduce the risk of such transmission. Even if she were sure that she would receive the blessing of her fellow villagers, Sarah would not have chosen to give birth to a child without the support of health workers such as Yafet.

Yafet supports childbirth by HIV-positive individuals because it is the most realistic option. Some women will want to have children regardless of opposition from health workers, whereas others may become pregnant even if they are hesitant to do so. If HIV-positive women felt that health workers were opposed to their having children, they would be likely to stop visiting health centers,

and this would create a very dangerous situation. It is estimated that HIV-positive women who experience natural childbirth without receiving appropriate treatment and then breastfeed their newborns face a 35% risk of mother–child transmission (WHO, 2009).

It seems that local health workers are increasingly confident about preventing mother–child transmission in the healthcare settings of sub-Saharan Africa. Their confidence is supported by epidemiological evidence demonstrating that the risk of mother–child transmission can be reduced significantly if the expectant mother and newborn both receive HIV treatment. By taking appropriate measures, it is possible to reduce the risk of mother–child transmission to below 5% in low-income countries (WHO, 2009). In a clinical trial in Botswana, mother–child transmission was reportedly reduced to 1.1% through the use of antiretroviral drugs (Shapiro et al., 2010).

Furthermore, assuming that mothers will also receive drug treatment to prevent transmission, it is recommended that newborns in low-income countries be breastfed until the age of six months. This is because the risk of infant mortality due to other infectious diseases will increase if mothers insist on feeding their babies with formula. According to WHO statistics, 10.4% of infants in Ethiopia die before reaching the age of five; this stands in stark contrast to the situation in rich nations, where infant mortality is 0.8% (WHO, 2011). In Ethiopia, where the possibility of death due to diarrhea or other common infectious diseases is not small, HIV infection does not necessarily constitute the biggest risk for newborns.

Health workers not only have information about the technologies used to reduce the risk of HIV transmission but also understand the limitations of local healthcare systems. Furthermore, health workers such as Debritu and Yafet have an intimate understanding of how HIV can impact the life courses and economic situations of individuals and their families in rural communities. They have adopted the attitude of supporting the household economy and childbearing decisions of HIV-positive individuals by creating the social conditions necessary for living with the virus. It is through dialogue between such health workers and local inhabitants that the knowledge and ethics necessary for a society living with HIV will develop.⁽¹⁴⁾

CONCLUSION

In this paper, I examined knowledge, institutional settings, and ethical issues related to living with HIV in rural Ethiopia and explored how a society faced with an invasion by a pathogen can best ensure the survival of its members while at the same time promoting their quality of life.

The development of global health has altered the technological and institutional foundation for human survival on a global scale. At the same time, global health interventions can alter many aspects of the relationships between individuals and present novel ethical dilemmas. Global HIV interventions have resulted in longer life expectancies among people with HIV in sub-Saharan Africa. However, living with HIV is not the same as simply increasing the life expectancies of individuals with the virus. It entails that infected persons continue in their efforts to lead

meaningful lives by developing affirmative relationships despite the epidemiological fact that those who are infected pose a health risk to others.

In the present era of global health, we have the opportunity to consider how to structure social institutions so that they utilize the knowledge and technologies necessary for individuals to lead meaningful lives. The role played by a number of health workers in rural Gurage is a good example. They not only understand what constitutes risky behavior in the context of infectious disease epidemiology but also are in a position, through dialogue with community members, to understand what meaning such risky behaviors hold in terms of people's life courses. Health workers stand on the technological and institutional foundation of global health and play a critical role in rural communities in encouraging efforts by both HIV-positive and HIV-negative individuals to live together and lead meaningful lives.

A number of Gurage women have lost their husbands to AIDS and are now living with HIV. Given that these women could present a risk of HIV transmission to other local residents through their sexual relations and to their children through childbirth, they are prone to experiencing severe poverty and social isolation. However, as demonstrated in this paper, we can also observe practices among some Gurage villagers that support the livelihoods of such women; these examples demonstrate actual possibilities of developing affirmative relationships between those who are infected with HIV and those who are not. Such practices teach us that we can facilitate affirmative relationships with others even when some of these relationships may involve an epidemiological risk to ourselves.

NOTES

- (1) For example, the disease-related mortality rate of British soldiers stationed in Sierra Leone in the early 19th century increased to 483 per 1,000, much higher than the mortality rate due to combat. It is believed that the majority of these deaths by disease were due to malaria (Curtin, 1989).
- (2) However, Garrett (2007: 16) also argued that individual global health programs operated by administrators in wealthy countries are not as effective as they could be due to inappropriate management and lack of sustainability.
- (3) According to a report based on a cohort study conducted in Uganda, a 35-year-old HIV patient could expect, on average, to live an additional 27.9 years; this does not substantially differ from the national average additional life expectancy of 30.1 years (Mills et al., 2011). Note that the study also reported considerable variability by age, sex, and CD4 count at the time of initial treatment.
- (4) However, creation of environments conducive to the malaria mosquito through agricultural development and deforestation, development of insecticide-resistant mosquito strains, and regulation of insecticide use resulting from environmental concerns has rendered conventional management of malaria difficult to the point that it is now believed that the eradication of malaria is impossible. This, combined with a weak healthcare infrastructure, has led to a substantial increase in malaria-related deaths since the 1970s, particularly in sub-Saharan Africa (Carter & Mendis, 2002: 582).
- (5) VCT refers to the practice of providing counseling and HIV screening to only those individuals who visit a healthcare facility at their own instigation with the purpose of receiving HIV testing. In recent years, the adoption of provider-initiated screening,

- whereby medical professionals proactively offer HIV screening, has been recommended for the purpose of promoting more extensive HIV screening (WHO, 2007).
- (6) The World Bank, United Nations agencies, and donor countries have proactively supported Ethiopia's HSDP from the standpoint of alleviating poverty.
 - (7) More specifically, health extension workers are, as a general rule, deployed to their village (*kebele*) or peasant association of origin, the administrative unit below district. However, due to personnel shortages, it is common for individuals to be placed in *kebele* or peasant associations in areas other than their communities of origin (Teklehaimanot et al., 2007).
 - (8) Meanwhile, many problems with the national scheme to deploy health extension workers have been noted. Efficient management of the system is hindered by problems such as the shortage of materials and equipment to be used by health extension trainees at the TVETs (Kitaw et al., 2007). Another problem is the lack of clear guidelines describing the responsibilities of health extension workers and their relationship with existing healthcare providers. (Teklehaimanot et al., 2007).
 - (9) Estimates based on interviews conducted by the author. Additionally, as the fiscal year in Ethiopia starts in July and ends in the June of the following year, 2008 refers to the year starting in July 2008 and ending in June 2009 both here and throughout this paper.
 - (10) Based on a story of the rediscovery of the lost cross used to crucify Jesus Christ, the Mesqal is a holiday celebrated by followers of the Ethiopian Orthodox Church.
 - (11) The health status of infected individuals varies, and not all individuals are able to perform manual labor as Ibrahim does. The majority of infected individuals receiving treatment are generally able to lead healthy, productive lives while experiencing various problems such as becoming tired more easily than before and suffering from the side effects of the drugs they are taking.
 - (12) Although he classified ensete cultivation as a sustainable, low-input agricultural practice requiring a minimal investment of labor and money, Shigeta also pointed out that it is labor-intensive in terms of post-harvest processing (Shigeta, 2002). Furthermore, the cultivation method employed by Gurage farmers usually involves multiple transplantations, making it more labor-intensive than it is elsewhere in Ethiopia.
 - (13) For HIV-positive individuals living in rural Ethiopian farm villages, securing money to pay for transportation to healthcare centers is a critical issue. It is the near-unanimous view of individuals involved in local health administration that, due to financial constraints, despite strong demand from villagers and health extension workers, there is little chance that subsidies to cover transportation costs will be provided in the near future.
 - (14) However, the experiences of health workers in rural communities have not necessarily been reflected in the Ethiopian healthcare system. In many cases, the problems identified by health extension workers have not been met with appropriate responses from policy-makers. The challenge today is to establish a system that takes full advantage of the creative proposals emerging from dialogues between health extension workers and community members.

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Author's Name and Address: Makoto NISHI, *Global Survivability Studies Unit, Kyoto University, 4, Ushinomiya-cho, Yoshida, Sakyo-ku, Kyoto 606-8302, JAPAN.*

E-mail: nishi [at] jafore.org

